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Managing Post-Stroke Fatigue: A Guide for Daily Living for Clients and Caregivers

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MANAGING POST-STROKE FATIGUE: A GUIDE FOR DAILY LIVING FOR CLIENTS AND CAREGIVERS

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This Scholarly Project Paper, submitted by Carolyn Krum, MOTS and Heather Satrom, MOTS in partial fulfillment of the requirement for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

Jan Stube
Faculty Advisor

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Signature Carolyn J. Krum Date April 30, 2008

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ABSTRACT

Several research studies have determined that fatigue is a common symptom, that should be viewed as an independent consequence following a stroke: it interferes with an individual's engagement in activities of daily living. Fatigue can be misinterpreted as depression, therefore, may be treated inappropriately or remain untreated. Fatigue is not often addressed by health care professionals, therefore, clients and their families are not receiving the proper education and resources to manage fatigue challenges (Glader, Stegmayr, & Aspuland, 2002; Schepers, Visser-Meily, Ketelaar, & Lindeman, 2006). The purpose of this project was to develop a guide for daily living for clients and caregivers to educate and manage post-stroke fatigue.

A literature review of journal articles was conducted to determine what has been done in the healthcare profession and the field of occupational therapy regarding management of post-stroke fatigue. Brief summaries of each of the articles were written to broaden knowledge and synthesize understanding of the topic. Common themes relating to post-stroke fatigue were identified from the scholarly literature and became the focus of discussion throughout the literature review: defining fatigue and how it differs from depression; exploring possible causes and risk factors; studying fatigue's impact on daily living and on caregivers; selecting appropriate measurements and assessments to further future research; and studying current suggested interventions and their effectiveness in managing post-stroke fatigue.

A guide for daily living to manage post-stroke fatigue was developed for clients and caregivers using adult learning principles. Adult Learning principles acknowledge that the learner takes the responsibility to make his or her own decisions. By increasing awareness of what the learner needs to know, individuals are able to make personal modifications and to effectively cope with real-life situations (Knowles et al., 2005). The contents of the guide address the most prevalent needs, as identified in the literature review, of individuals that are suffering from post-stroke fatigue and can be incorporated at any point within the rehabilitation process.

This guide for daily living focuses on the integral role played by an occupational therapist to assist clients and caregivers and provides educational information to enable management of post-stroke fatigue symptoms. The product facilitates the ability to define and identify post-stroke fatigue; to identify possible causes and risk factors; to recognize the potential impact on daily living; to seek further information from health care providers; and to provide post-stroke management strategies which include instructions for recognizing fatigue symptoms, energy conservation techniques, tips for staying active, and addressing the psychosocial aspects of living with fatigue.

CHAPTER I

INTRODUCTION

Prior to experiencing a stroke, many individuals led active, independent lives in which they had control over their environment and the ability to complete activities of daily living. Post-stroke, these individuals often encounter difficulty completing daily roles and routines because of a decline in energy, and as a result, these individuals experience many changes. Some of these changes may include greater limitations on functioning (Ingles, Eskes, & Phillips, 1999), a decline in mobility and level of activity (van de Port, Kwakkel, van Wijk, & Lindeman, 2006), a decline in peer interaction (Holberg & Finlayson, 2007), institutionalization, and experiencing poorer health (Glader, Stegmayr, & Asplund, 2002). Changes such as these can reinforce dependence in activities of daily living and can ultimately affect individuals' quality of life (Tyrrell & Smithard, 2006; van de Port, Kwakkel, Schepers, Heinemans, & Lindeman, 2007).

Recent studies illustrate that the frequency of fatigue can range from 30% to 68% among stroke survivors (Choi-Kwon, Han, Kwon, & Kim, 2005; Glader et al., 2002; Ingles et al., 1999; van der Werf, van den Broek, & Anten Gijs Bleijenberg, 2001). Fatigue often impacts occupational functioning both physically and cognitively (Glader et al., 2002; de Groot, Phillips, & Eskes, 2003) and many patients report that fatigue was either their worst symptom or one of their worst symptoms (Ingles et al., 1999; de Groot et al., 2003; Glader et al., 2002).

Post-stroke fatigue is a significant yet often disregarded concern (Tyrrell & Smithard, 2006) that can considerably impact an individual's daily routine; therefore, it is necessary to recognize and address fatigue in order to assist patients and their caregivers in anticipating, and essentially, in managing fatigue as it may affect their ability to function (Tyrrell & Smithard, 2006). In doing so, it is important for healthcare providers to: consider defining fatigue and how it differs from depression; explore possible causes and risk factors; study fatigue's impact on daily living and on caregivers; select appropriate measurements and assessments to further future research; and study current suggested interventions and their effectiveness in managing post-stroke fatigue.

One type of intervention that is being proposed in this scholarly project is a manual for daily living for clients and caregivers to address post-stroke fatigue. This educational guide, which can be utilized in all stages of the recovery process, will assist in the management of post-stroke fatigue symptoms to facilitate quality of life and well-being. The content of the guide is valuable for both clients and their caregivers. It is the hope that this guide will stimulate self-reflection and discussion with their occupational therapist and/or other healthcare providers in order to recognize and manage post-stroke fatigue.

Adult Learning Theory was selected for the development of the product due to "the fact that adults engage in an educational activity because of some innate desire for the developing of new skills, acquiring new knowledge, improving already assimilated competencies, or sharpening powers of self-insight…" (Brookfield, 2002, p. 11). Adults have preferred and varying ways in which they process information, and adults are more willing to engage in learning if the learning is meaningful to them (Caffarella, 2002).

Furthermore, adults learn best when they are presented with something they can apply in real-life situations (Knowles, Holton, & Swanson, 2005).

This product was designed to address the fact that adults either learn interdependently, connected, and collaboratively, or independently and self-reliant. Regardless of the learning style, an adult voluntarily participates and engages in the learning process of their own volition, possibly prompted by circumstances external to the learner (Brookfield, 1986). Adult learning provides the learner with responsibility to make their own decisions. By increasing awareness of what the learner needs to know, individuals are able to make personal modifications and to effectively cope with real-life situations (Knowles et al., 2005).

This product also addresses various roles and environments, which allows individuals to apply the information to personal goals and objectives. The learning style of adults is pragmatic, and they desire to apply what they are learning to their current situation (Caffarella, 2002). They prefer to not be passive in gaining knowledge, but rather they desire to be an active participant in the learning process.

In addition, clients and caregivers are able to utilize this product in the comfort of their own environment and at a time that is convenient for them. It has been theorized that when learning situations are physically and psychologically relaxed, adults are more engaged and receptive to the process of learning (Caffarella, 2002). The guide can also be utilized in a group setting or on an individual basis, with opportunities provided throughout for self-reflection to maintain or enhance self.

The remainder of this scholarly project includes a review of current literature regarding post-stroke fatigue, activities and methodology used to design the product, a

product to be utilized by clients and caregivers to manage post-stroke fatigue, and a summary of the product which includes strengths, limitations, and usefulness.

CHAPTER II

REVIEW OF LITERATURE

Defining Fatigue

As described in the research conducted by Piper et al. (as cited in Michael, 2002), "fatigue is a multicausal, multidimensional sensation that affects sensory, affective, behavioral, and physiologic realms" (p. 91). One definition created by Aaronson et al. (1999) took into consideration the variety of factors and defined fatigue as "The awareness of a decreased capacity for physical and/or mental activity due to an imbalance in the availability, utilization, and/or restoration of resources needed to perform activity" (p. 46).

The complexity, imprecision, and factors relating to post-stroke fatigue are problematic in the development of an understandable and objective definition due to the fact that a definition is influenced by cultural factors, social factors, and psychological functioning (Aaronson et al., 1999). Fatigue is experienced amongst the majority of chronic diagnostic populations, and lacks a universal definition in which to categorize and measure for research purposes in order to develop appropriate interventions for treatment. Without a concrete definition, this symptom remains undiagnosed and untreated by health professionals. Eidelman stated (as cited in Aaronson et al., 1999), "The absence of an overall definition of fatigue preempts any scientific basis for measuring the condition, because logically, that which cannot be defined cannot be measured, and is not understood" (p. 46).

Chaudhuri and O Behan (2004) completed a review of current literature to develop understanding of fatigue in various neurological disorders. According to Chaudhuri and O Behan (2004), self-perceived fatigue is subjective, and therefore best defined clinically as "difficulty in initiation of or sustaining voluntary activities" (p. 978). It may occur in response to activities involving continued effort or as a primary condition linked with continuous exhaustion (Tyrrell & Smithard, 2006). Ingles, Eskes, and Phillips (1999) define fatigue as a "feeling of physical tiredness and lack of energy" (p. 174).

Staub and Bogousslavsky (2001) distinguished fatigue as objective or subjective, and further classified fatigue into subtypes including physical, somatic, mental and psychological fatigue. Objective fatigue is defined as the "observable and measurable decrement in performance occurring with the repetition of a physical or mental task" (p. 3). In contrast, subjective fatigue is defined as "a feeling of early exhaustion, weariness and aversion to effort" (p. 3).

Fatigue has further been characterized as (a) chronic versus acute, (b) normal versus pathological and psychological; or (a) normal fatigue as acute, and (b) pathological as chronic fatigue (Aaronson, et al., 1999). As defined by a study conducted by Swain (2000), chronic or pathological fatigue accompanies medical illnesses, persists longer than 6 months, has multiple unknown origins, is not relieved by rest, and more than likely has no relation to exertion. In a study by de Groot, Phillips, and Eskes (2003), pathologic fatigue was defined as "a state characterized by weariness unrelated to previous exertion levels and is usually not ameliorated by rest" (p.1715).

In contrast, acute fatigue can be self-limited, the origin is identifiable, occurs in individuals without health problems, and appropriate rest will relieve the symptom

(Swain, 2000). Normal fatigue was defined by de Groot et al. (2003) as "a state of general tiredness that is the result of overexertion and can be ameliorated by rest" (p. 1715). They further classified fatigue according to the onset and duration of its course. According to this classification, normal fatigue has a shorter duration and is likely triggered by a single source, whereas pathological fatigue is more chronic and likely triggered by multiple sources (de Groot et al., 2003).

Depression and Post-Stroke Fatigue

According to Staub and Bogousslavsky (2001), there are numerous descriptors used to define fatigue; however, some descriptors make it difficult to distinguish depression-related symptoms from fatigue-related symptoms. Depression appears to be the only impairment that has an unquestionable relation to post-stroke fatigue (Schepers, Visser-Meily, Ketelaar, & Lindeman, 2006). Michael (2002) stated that "fatigue may worsen other symptoms such as depression or weakness" (p. 89).

In comparison of a patient and control group in a study conducted by van der Werf, van den Broek, and Anten Gijs Bleijenberg (2001), physical impairments, depression, and neuropsychological complaints were related to the level of fatigue that was experienced by the patient group. Participants that were within the control group did not have physical impairments, reported no extreme fatigue, and minimal elevation in depression. From the results, it could be hypothesized that physical impairment was a precursor to reactive depression that resulted in fatigue. However, these findings are not conclusive and other factors that were not purposefully taken into consideration throughout the study could have had effects on the outcome.

While it is important to note that post-stroke fatigue can occur in conjunction with depression, it can also develop independently. Although fatigue is often a symptom used to define depression (Choi-Kwon, Han, Kwon, & Kim, 2005; Tyrrell & Smithard, 2006; van de Port, Kwakkel, Schepers, Heinemans, & Lindeman, 2007), several studies illustrated that fatigue can occur independent of depression after stroke (Choi-Kwon et al., 2005; Glader, Stegmayr, & Asplund., 2002; Ingles et al., 1999; Staub & Bogousslavsky, 2001; van der Werf et al., 2001). Schepers et al. (2006) concluded that 75% of the patients in their research study who experienced moderate to high fatigue did not suffer from depression, although it was a determining factor of the impact of fatigue within the study. Therefore, depression may influence post-stroke fatigue levels.

According to Ingles et al. (1999), a significant number of participants experienced fatigue without feelings of depression; however, depression was also shown to influence the impact of fatigue on functioning and therefore they may be associated in some patients. Choi-Kwon et al. (2005) illustrated similar findings in that post-stroke fatigue could occur independently in patients without depression. Results also show that about one third of all stroke participants experienced depression and that post-stroke depression was independent of post-stroke fatigue. Due to these results, it is important for individuals post-stroke to complete clinical screening of both fatigue and depression in order to receive optimal treatment and to maximize recovery (Ingles et al., 1999; van de Port, Kwakkel, van Wijk, & Lindeman, 2006).

Potential Causes and Risk Factors of Fatigue

Due to the multidimensional qualities of post-stroke fatigue (Chaudhuri & O Behan, 2004; Staub & Bogousslavsky, 2001), there may be several possible causes and

risk factors affecting this symptom. However, due to the limited research available, there are currently few identified predictors of post-stroke fatigue (de Groot et al., 2003) and the causation is relatively unknown (Tyrrell & Smithard, 2006).

In a two year follow-up study by Glader et al. (2002), pre-stroke factors that were associated with post-stroke fatigue included institutionalization, dependence in ADLs, living alone, preceding strokes, and increasing age. Stroke subtype was not associated with fatigue. At two years post-stroke, self-reported fatigue was associated with poor general health, anxiety, pain, and depression.

Ingles et al. (1999) completed a study to identify characteristics of post-stroke fatigue including demographic information, medication utilization, co-morbid health conditions, and stroke-related variables. Results from the study illustrated that co-morbid health conditions, medication use, and age were not found to have a greater effect on fatigue in patients post-stroke when compared with the control group. In addition, stroke related variables including lesion location, time since the stroke occurred, and the type or severity of stroke did not appear to influence fatigue in patients post-stroke.

In a study by Choi-Kwon et al. (2005), post-stroke fatigue was associated with unemployment, change in employment, cigarette smoking pre-stroke, remaining neurological deficits, dysarthria, insomnia, and loss in appetite. In addition, post-stroke fatigue was independently associated with pre-stroke fatigue, high Modified Rankin scale, post-stroke depression, and decreased sexual activity. Similar to the study by Ingles et al. (1999), lesion location, lesion size, and current medications were not related to post-stroke fatigue.

Researchers of post-stroke fatigue have studied a variety of potential origins of this universal symptom. Jaracz, Mielcarek, and Kozubski (2007) indicated that the authors of existing research have primarily focused on whether post-stroke fatigue is a specific consequence, or whether it is a symptom and consequence of other post-stroke impairments and deficits. Swain stated, "It is not known whether fatigue in a given disease is a consequence of simply being chronically ill, or whether it represents a specific complication of that disease. The poor correlation between fatigue and traditional markers of disease severity appear to support the latter" (2000, p. 2). When individuals complain of fatigue post-stroke, the symptom is viewed as temporary, directly resulting from impairments in function, psychological distress, and recovery (van der Werf et al., 2001).

Swain (2000) divided the origin of fatigue into two categories, central or peripheral. However, these two types can coexist. Central fatigue is often associated with psychological complaints, and there is an implication of abnormalities or alterations within the central nervous system (CNS) of the neurotransmitter pathways. Central fatigue can be present in disorders of the peripheral, autonomic, or central nervous system (Chaudhuri & O Behan, 2004) and is a result of an imbalance between motivation and perceived effort (Staub & Bogousslavsky, 2001; Chaudhuri & O Behan, 2004). Peripheral fatigue, on the other hand, is the consequence of dysfunction of the neuromuscular system external to the CNS, and impairments of neurotransmission within peripheral nerves and/or muscle contraction defects. Peripheral fatigue is characterized by muscle weakness or an objective decline in motor output. In contrast, central fatigue is characterized by perception of fatigue and is therefore subjective.

Funk proposed (as cited in Michael, 2002), a neurophysiologic model to describe how fatigue affects the central and peripheral nervous system, which confirms the research conducted by Swain (2000). Central fatigue results in decreased levels of motivation, a decrease in the number of messages transmitted to the spinal cord from the brain, and brain cell fatigue within the hypothalamic region. Interactions between nerve and muscle that stimulate force and movement are altered with peripheral fatigue.

Patients diagnosed with a chronic disease have a more relevant relation to central fatigue; therefore, Swain (2000) has described theories which explain the origin of central fatigue as it pertains to chronic disease. The three theories discussed are corticotropin-releasing hormone (CRH) and chronic stress, cytokines and immune activation, and central neurotransmitter pathways.

CRH is a hormone that activates the hypothalamic-pituitary-adrenal axis to stimulate the release of adrenocorticotropic hormone, or ACTH (Swain, 2000). It has an important role with the activation of behavioral responses or changes, as when the body is stressed, due to the hormone's presence in the limbic and autonomic structures within areas of the brain. Therefore, it has been hypothesized that a defect with the release of central CRH may lead to behavioral depression, and ultimately to fatigue. Claus and Chrousos along with Bearn, Allain, and Coskeran (as cited in Swain, 2000) further supported this hypothesis with the results of their studies of individuals with chronic fatigue syndrome in which it was consistently suggested an impairment existed in the synthesis and release of central CRH within the hypothalamus.

As suspected by Bruno et al. (as cited in Staub & Bogousslavsky, 2001):

> ...viral damage to reticular formation, lenticular, hypothalamic and thalamic nuclei, cortical motor areas and especially dopaminergic neurons in the substantia nigra was responsible for the development of a feeling of fatigue, exhaustion and aversion to effort, by causing a decrement in cortical activation, with attentional impairment, slowing of information processing speed and inhibition of motor activity. (p. 78)

The stimulation of cytokine release is coordinated with the acute-phase in response to inflammation, and with illnesses has been associated with the development of non-specific symptoms such as fatigue (Swain, 2000). Specifically, cytokine interleukin or IL-6, is present in a variety of chronic diseases. It is unknown how cytokine levels external to the CNS are increased and produce alterations in behavior, but there may be a link with the penetration of cytokine in areas of the brain where the blood-brain-barrier is not present. According to Tyrrell and Smithard (2006), activation of the brain cytokine system, particularly interleukin, allows physiologic symptoms such as fatigue to occur in order to respond effectively to infection. Therefore, it is suggested that these proinflammatory cytokines may be responsible for post-stroke fatigue by impairing glutamate neurotransmission.

In the final theory proposed by Swain (2000), the serotonergic and noradrenaline neurotransmitter system pathways are associated with the development of fatigue due to the systems control over the release of CRH. Serotonergic neurons synapse with neurons containing CRH within the hypothalamus, and serotonergic pathways are activated to release CRH when induced by stress. However, when this system is altered or defective, central fatigue develops.

Furthermore, Glader et al. (2002) suggest that fatigue is the result of an organic brain lesion in addition to ineffective coping with a new condition post-stroke. It is further suggested that the relationship between fatigue and the decline in functional ability may be reciprocal; therefore, fatigue may affect general health and functional ability and a decline in functioning and general health may affect fatigue (Glader et al., 2002; van de Port et al., 2006).

Impact of Fatigue on Daily Living and Caregivers

Cooper et al. stated (as cited in Michael, Allen, & Macko, 2006), "Loss of independence in such basic activities hampers personal freedom, reduces autonomy, and renders individuals with stroke vulnerable to the detrimental physical and psychosocial effects of physical inactivity" (p. 216). It is unfortunate that individuals suffer from and learn to live with post-stroke fatigue. Recent studies have demonstrated the impact of post-stroke fatigue on functioning; however, this remains unclear in the literature (de Groot et al., 2003).

According to Swain (2000), patients diagnosed with a chronic disease have identified fatigue as a primary factor in the decrease of their quality of life. This symptom has an impact on a person's daily life, their ability to function, level of independence, roles inside and outside of the home, and relationships with others (Michael, 2002). Glader et al. (2002) completed a follow-up study to discover the impact of fatigue on daily living and survival in patients post-stroke. Results from the study showed that fatigue is associated with dependence in activities of daily living (ADL), institutionalization, poor perceived general health, and speech impairment 2 years post-stroke. Furthermore, fatigue was shown to be an independent predictor for dependence in

ADL and a decline in health 2 years post-stroke, independently of depression, and as a predictor for mortality 3 years post-stroke.

According to Michael et al. (2006), individuals that suffered from a stroke indicated that their dependency in completing primary ADL, and the reason for moving into an institutional environment, was primarily due to fatigue. Furthermore, fatigue is present in conjunction with a disability and has effects on physical, psychological, behavioral, and self-care functions.

For those individuals with chronic stroke, the severity of deficits with mobility and deconditioning of the cardiovascular system are associated with fatigue and the consequence is a decrease in ambulation activities within the home and community (Michael et al., 2006). Results from this study illustrate that participants did not have the functional aerobic capacity necessary to complete basic ADL functions due to decreased cardiovascular fitness levels.

Research participants within the study conducted by Michael et al. (2006) have self-rated experiencing the most severe fatigue in physical functioning, exercise behavior, and motivation levels. Additionally, due to the severity in their levels of fatigue, these individuals had the least amount of confidence to avoid falling while participating in ADL. Fatigue has lead to a reduction in activity, consequently to deconditioning, decrease in strength, and a decline in balance and gait.

Other important factors to consider when discussing post-stroke fatigue are: at what point following a stroke the symptom will occur, the frequency, and the duration of symptoms. In a study by Choi-Kwon et al. (2005), 77% of patients experienced fatigue within the first week after the onset of stroke and 44% reported that fatigue was present

on more than 20 days per month. Ingles et al. (1999) reported that 27% of stroke patients experienced fatigue on a daily basis. Van der Werf et al. (2001) determined that fatigue continues to be a severe, frequent, and persistent symptom that can occur long after a stroke. These findings suggest that fatigue is persistent and were shown to affect cognitive, psychological, and physical activities with the largest effect on physical versus psychosocial or cognitive activities (Choi-Kwon et al., 2005; Ingles et al., 1999).

A prospective cohort study by van de Port et al. (2007) illustrated that post-stroke fatigue is associated with instrumental activities of daily living (IADL) and heath related quality of life between 6 and 36 months post stroke; basic ADL functioning was not affected by fatigue, however IADL was. Another prospective cohort study by van de Port et al. (2006) found that 21% of patients experienced a decline in mobility between 1 and 3 years post-stroke. Fatigue was shown to be a significant predictor for this decline in mobility along with cognitive dysfunction, depression, and poor activity level.

Schepers et al. (2006) concluded that there is an increase in fatigue impact throughout the first year following a stroke. However, this may be attributed to the fact that initially stroke patients are learning to manage or are recovering from other impairments. They are not focused on or may not even be aware that they are suffering from fatigue. Although, their awareness of the symptom may become more prevalent as they attempt to resume work roles, participate in social engagements, or when there is an increase in the demands of their daily lives.

Due to the decline in functioning post-stroke, stroke care is necessary following hospital discharge and the responsibility is often placed upon family members of the

stroke survivor (Sit, Wong, Clinton, Li, & Fong, 2004). Current literature illustrates the impact of the caregiving role on the health of family caregivers.

Sit et al. (2004) found that 83 percent of caregivers experienced fatigue and stress from the demands of caregiving during the initial 12-week period following discharge from the hospital. Caregivers experienced difficulty in balancing caregiving and familial roles, and 65 percent of subjects experienced feelings of confinement. In addition, about 40% of caregivers experienced somatic symptoms after 12 weeks. Sit et al. (2004) further reported the need for professional support in order to assist in home and community care, particularly following hospital discharge. Clear and comprehensive education for caregivers of all educational backgrounds is essential.

Assessment Recommendations for Post-Stroke Fatigue

Due to the fact that post-stroke fatigue has been relatively overlooked (Glader et al., 2001; Ingles et al., 1999; Staub & Bogousslavsky, 2001), little information is available regarding assessment of fatigue in patients after stroke. Unsuccessful efforts to find an objective method of measuring fatigue may be due to the multidimensional qualities and subjective nature of fatigue (de Groot et al., 2003; Staub & Bogousslavsky, 2001; Tyrrell & Smithard, 2006; Welham, 1995). Therefore, it is suggested that a multidimensional instrument (Staub & Bogousslavsky, 2001; Tyrrell & Smithard, 2006) and a multidisciplinary approach are necessary to evaluate fatigue (de Groot et al., 2003).

In regards to the necessity of utilizing valid and reliable measurements in which to study fatigue, Aaronson et al. (1999) stated the following:

> ...given the general lack of consensus in the literature on a definition of fatigue, it is not surprising that measuring (and, therefore, studying) fatigue has challenged

scientists for decades. Often a measure of fatigue is tailored to the situation in which fatigue is studied, further limiting generalization of findings. Measuring fatigue has been hindered not only by its ubiquitous nature but also because fatigue is a symptom and, as such, its subjectivity presents additional measurement difficulties.

Thus, definitional difficulties and an absence of a gold standard measure of fatigue have seriously limited efforts to synthesize common knowledge about fatigue. (p. 46)

A stroke may result in significant weakness, but individuals may not characterize themselves as fatigued even though the weakness appears more evident due to the fatigue (Michael, 2002). The ambiguous and multidimensional nature of fatigue complicates the utilization of appropriate assessments to measure the effects of post-stroke fatigue on an individual and their ability to perform daily activities. Obviously, it is important to start with patient report on how the symptoms of fatigue are impacting their lives. As stated by Staub and Bogousslavsky (2001), a distinction must be made between feeling fatigued and objective physical fatigue, which has a definitive and exact origin.

The assessment of post-stroke fatigue, as suggested by de Groot et al. (2003), should consist of a physical examination to determine history and personal characteristics, a set of criteria specific to post-stroke fatigue, and the use of objective assessment tools for measurement. Furthermore, Michael reported (2002) that the compilation of patient information be initiated during the rehabilitation process. A detailed history should include a timeline, intensity level, how fatigue is aggravated, how is fatigue alleviated,

current medications, sleeping habits, nutrition, effects of fatigue on daily activities, depressive symptoms, physical examination, and complacency with treatment plan.

Current research (Glader et al., 2002; Ingles et al., 1999; Van der Werf et al., 2001) incorporates the use of fatigue scales developed for conditions other than stroke; therefore, the validity of such scales in stroke survivors has not been determined (Mead et al., 2007). Mead et al. (2007) completed a study to examine various fatigue scales and their validity, feasibility, and reliability in patients post stroke. Results from the study illustrate validity and feasibility in four scales of the 52 scales identified; these include the SF-36v2, the fatigue subscale of the Profile of Mood States (POMS), Fatigue Assessment Scale (FAS), and the general subscale of the Multidimensional Fatigue Symptom Inventory (MFSI).

Additional fatigue scales have been discussed in the literature. The Fatigue Impact Scale is a self-report assessment that requests participants to rate the level of impact fatigue has had on functional limitations and quality of life (Fisk et al., 1994). The researchers adopted the viewpoint of the Canadian Multiple Sclerosis Research Group that "measuring the effect of fatigue on activities . . . is more sensitive than simply asking patients to rate fatigue" (p. S79). However, self-report can have negative aspects as reported by van der Werf et al. (2001) that this type of report may not objectively indicate the experience of mental or muscle fatigue, but may only describe the additional effort required to compensate for a disability.

Additional ramifications of current assessments which measure fatigue include the possibility of an overlap in questions between two instruments consequently influencing research results (van de Port et al., 2007). Some fatigue scales may be

lengthy, reducing response rates (Ingles et al., 1999), while others may not be appropriate for persons with cognitive impairments considering the neurological effects of stroke (Mead et al., 2007). In addition, the use of various fatigue scales makes comparison between studies difficult (Ingles et al., 1999).

Aaronson et al. (1999) identified characteristics in which to define and measure fatigue as: subjective quantification, subjective distress due to fatigue, subjective assessment of the effects of performing activities of daily living, common recognizable correlates, and important biological parameters. Furthermore, an assessment does not exist that completely captures the complex nature of fatigue. Therefore, it is important for future researchers to identify what aspect of fatigue is relevant to the study and select an appropriate measurement versus selecting an assessment that measures additional aspects of fatigue that may not be relevant to the research.

Future assessments to be utilized for measurement of fatigue should also take into consideration individuals that may have cognitive deficits or impairments in communication in order to eliminate bias to certain patients within the stroke population (Michael, 2002). In addition, benefits could be gained from utilization of behavioral measures for physical functioning and cognition (van der Werf et al., 2001). Future studies should utilize objective measurements, as they are more conceptually desirable when compared with subjective measurements of fatigue; however, they have received minimal attention (Swain, 2000).

Intervention Recommendations to Manage Post-Stroke Fatigue

Therapies specific to the treatment of fatigue are lacking due to the subjective nature of the symptom, therefore, post-stroke fatigue remains largely undiagnosed and

untreated by clinicians (Swain, 2000). If health care professionals are not knowledgeable about the prevalence of fatigue in chronic disease, patients will remain ignorant as to why and how to regain a quality of life post-stroke. Through the understanding and designing of fatigue management strategies, there could consequently be greater success for recovery and functional results in stroke patients (Michael, 2002). Schepers et al. (2006) expressed the following:

> In patient education, which is a first and important step in the management of fatigue problems, health care professionals must inform patients about the likelihood of experiencing fatigue after suffering a stroke, even long after the event. This will enable patients and their families to anticipate future problems and allow them to gain recognition for this problem. This may diminish distress and misunderstanding when fatigue problems occur (p. 186).

Swain (2000) identified several approaches to include regarding a multifaceted therapeutic intervention for treating individuals with post-stroke fatigue. This multifaceted intervention includes the following three components. First, exclude other common treatable diagnoses that may be occurring in conjunction with the chronic disease and exclude the presence of mood disorders. Secondly, teach energy conservation strategies and prioritizing of daily activities. Thirdly, create a balance between activity and rest. Furthermore, grade aerobic activities if the individual does not have physical impairments. If disability is a concern, Tyrrell and Smithard (2006) suggest chair-based exercises or other suitable exercise programs.

Other therapeutic intervention approaches have also been proposed such as patient/family education, cause-specific treatments, nonpharmacologic, and

pharmacologic treatments (Michael, 2002). Through therapeutic education and counseling, patients and family members can learn to identify activities that facilitate fatigue, modify fatigue-provoking activities, utilize energy conservation techniques such as prioritizing or delegating, structure daily activities with required rest, and make adaptations to the environment in order to manage symptoms.

Nonpharmacological Intervention

Occupational therapy provides energy conservation education programs, a nonpharmacological approach proven effective in managing fatigue (Matuska, Mathiowetz, & Finlayson, 2007). Shapiro (as cited in Mathiowetz, Matuska, & Murphy, 2001), defined the role of occupational therapists as "efficiency experts", and are therefore uniquely qualified to educate individuals in energy conservation strategies, management of time, proper body mechanics, and performance of a task. Furthermore, the purpose of the occupational therapy profession "is to enable individuals to participate in self-care, work, and leisure activities that they want or need to perform" (Mathiowetz et al., 2001).

Endurance is impaired by the symptom of fatigue, which can affect role or occupational performance. If this impairment exists, it is necessary to provide education on energy conservation strategies. Energy conservation strategies can include, but are not limited to: prioritizing and engaging in activities that are most important; simplification of work by decreasing the amount, pre-planning, utilizing appropriate body mechanics, and utilizing efficient methods and proper equipment; and adequate rest (Mathiowetz et al., 2001).

Packer, Brink, and Sauriol (as cited in Mathiowetz et al., 2001), described occupational therapists using "active learning activities" within energy conversation education to facilitate self-efficacy of participants in order to self-manage the symptoms of fatigue following multiple sclerosis (MS). The results of the study on the efficacy of an energy conservation course for persons with MS conducted by Mathiowetz et al. (2001) described that the active learning activities provided the opportunity for participants to apply the strategies learned to their daily lives. At the conclusion of the six-week course, at least six of the energy conservation strategies were implemented in the daily lives of eighty percent of the participants, significantly less fatigue impact was felt by the participants, and there was a significant increase in self-efficacy and quality of life.

Energy conservation courses are often provided in a one-on-one setting; however, Matuska et al. (2007) illustrate the effectiveness of a 6-week community-based program offered in a group format. This type of course design provided sufficient time in between sessions to learn and implement various strategies into daily routines. These courses are effective in addressing both personal and environmental barriers to improve fatigue management and ultimately, to improve quality of life.

This group format reduced feelings of isolation that individuals who suffer from fatigue may experience due to its impact on occupational and role performance (Mathiowetz et al., 2001). Furthermore, the participants were able to bond with one another and developed a support system in which they could share their successes and difficulties in management of fatigue. Participants could discuss and receive feedback on successful outcomes of energy conservation strategies that they applied within their lives or they could discuss alternative methods to encourage success. Learned energy

conservation strategies were reinforced, shared problem solving, and encouragement to change behaviors all evolved out of the group format.

Furthermore, a systematic review by Steultjens et al. (2003) illustrates the efficacy of comprehensive OT in improving ADL, IADL and social participation in stroke rehabilitation. Comprehensive OT involves several intervention strategies including: training of sensory-motor functions, training of cognitive functions, training of skills such as dressing, advice and instruction regarding assistive devices, provision of splints, and education of family or the primary caregiver. These results confirm the importance of OT in multidisciplinary rehabilitation for patients after stroke.

Although patients are primarily responsible to comply and adhere to post-stroke fatigue intervention, it is just as important to involve family members and friends. Michael et al. (2006) stated that it may be equally important to include family and friends to assist in identifying and reinforcing fatigue management strategies to facilitate success, and to provide continuous social support. Tyrrell and Smithard (2006) additionally suggest utilization of psychosocial support to assist in development of positive coping strategies and most importantly to increase awareness for patients and their caregivers of the possibility of post-stroke fatigue.

A multifaceted approach may also include management of nutrition and metabolism. Stroke patients that have been inactive or have suffered from an illness for a prolonged period of time may experience deficits in their nutritional and metabolic status (Michael, 2002). Consequently, this may lead to a reduction in oxygen being transported by the blood, which leads to fatigue or loss of energy. Therefore, a possible treatment may be altering the imbalance in electrolytes to restore energy.

Matsen (as cited in Michael, 2002) defined nonpharmacologic interventions as the use of adaptive equipment to facilitate engagement in a consistent exercise routine which is individualized to elicit benefits both physically and psychologically. Restorative activities, therapeutic recreation, biofeedback, relaxation techniques, meditation, and pet therapy are additional interventions that have been suggested to distract an individual from feelings of fatigue and to reduce stress (Michael, 2002). Cognitive behavioral therapy (i.e., identifying thought patterns that may be contributing to fatigue and teaching self-help techniques in order to change behaviors) is another therapy available in treating fatigue (Swain, 2000).

Pharmacological Intervention

Schepers et al. (2006) suggested the utilization of pharmaceutical treatments, specifically selective serotonin reuptake inhibitors (SSRIs) which are used to treat symptoms of depression, for the treatment of fatigue. This was suggested due to the fact that there is evidence indicating that SSRIs assist in the reduction of fatigue experienced with patients who have multiple sclerosis and cancer. Although there is no specific treatment for post-stroke fatigue, Tyrrell and Smithard (2006) suggest the use of an anti-inflammatory to lessen symptoms that occur as a result of infection. Additionally, pharmacological management of factors such as pain, spasticity, and disrupted sleep should be treated as they affect the severity of fatigue (Tyrrell & Smithard, 2006).

Summary

Michael stated (2002), "For stroke patients, fatigue should be recognized, evaluated, monitored, documented, and treated at all stages, from the acute event through treatment and rehabilitation, to long-term recovery" (p. 92). Based upon this review of

existing literature regarding post-stroke fatigue, both professionals and patients lack awareness of this prevalent and common symptom. Patient education in managing post-stroke fatigue is essential in promoting quality of life.

This chapter focused on: the varying definitions of fatigue and how it differs from depression; probable causes and risk factors of post-stroke fatigue; the impact of fatigue on daily living and on caregivers; the importance of selecting appropriate measurements and assessments to further future research; current, suggested interventions and their effectiveness in managing post-stroke fatigue. Based upon findings of the literature review, a guide for daily living for clients and caregivers is necessary to promote self-management of post-stroke fatigue. The activities and methodologies of how this self-management product was developed will be explained in the following chapter.

CHAPTER III

ACTIVITIES/METHODOLOGY

The specific plan that was implemented to gather data and develop the product started with a comprehensive review of current literature to determine what has been done in the field of occupational therapy and/or other healthcare professions regarding management of post-stroke fatigue. Brief summaries of each of the articles were written to broaden knowledge and synthesize understanding of the topic.

The next step was to identify the common themes relating to post-stroke fatigue that emerged from the scholarly literature. Those themes were identified as and became the focus of discussion throughout the literature review: defining fatigue and how it differs from depression; exploring possible causes and risk factors; studying fatigue's impact on daily living and on caregivers; selecting appropriate measurements and assessments to further future research; and studying current suggested interventions and their effectiveness in managing post-stroke fatigue. Interventions that are currently being utilized to manage post-stroke fatigue were adopted from management of fatigue of individuals with Multiple Sclerosis (MS), Chronic Fatigue Syndrome (CFS), and other neurological disorders. Therefore, additional research is required to identify specific interventions for patients following stroke in order to facilitate evidence-based occupational therapy treatment.

Following the collection of data from current research and the composition of the literature review, a model was chosen to assist in the development of the format and

content of the product. Adult Learning Theory was selected due to "the fact that adults engage in an educational activity because of some innate desire for the developing of new skills, acquiring new knowledge, improving already assimilated competencies, or sharpening powers of self-insight..." (Brookfield, 2002, p. 11). Adults have preferred and varying ways in which they process information, and adults are more willing to engage in learning if the learning is meaningful to them (Caffarella, 2002). Furthermore, adults learn best when they are presented with something they can apply in real-life situations (Knowles, Holton, & Swanson, 2005).

Adult Learning principles provide the learner with the responsibility to make his or her own decisions. By increasing awareness of what the learner needs to know, individuals are able to make personal modifications and to effectively cope with real-life situations (Knowles et al., 2005). This product was designed to address the fact that adults either learn interdependently, connected, and collaboratively, or independently and self-reliant. However, regardless of their particular learning style, an adult voluntarily participates and engages in the learning process of their own volition, possibly prompted by circumstances external to the learner (Brookfield, 1986).

After the target audience was identified as post-stroke survivors and their caregivers, the product was developed. It was determined that the guide for daily living to manage post-stroke fatigue would be developed for clients and caregivers. The content would be based upon the most predominant needs identified from the literature review, and would be a valuable tool to facilitate quality of life and well being for both clients and caregivers. The product contains the necessary knowledge to enable management of post-

stroke fatigue symptoms by providing educational information to define and identify post-stroke fatigue; possible causes and risk factors; and the potential impact on daily living.

Shapiro (as cited in Mathiowetz, Matuska, & Murphy, 2001), defined the role of occupational therapists as "efficiency experts", and are therefore uniquely qualified to educate individuals in energy conservation strategies, management of time, proper body mechanics, and performance of a task as compared to other healthcare professionals. Furthermore, the purpose of the occupational therapy profession "is to enable individuals to participate in self-care, work, and leisure activities that they want or need to perform" (Mathiowetz et al., 2001).

Therefore, the contents of the guide focues on the integral role played by an occupational therapist in assisting clients and caregivers in identifying a variety of post-stroke management strategies including instructions for recognizing fatigue symptoms; using energy conservation techniques; tips for staying active; and addressing the psychosocial aspects of living with fatigue.

If provided on an individual basis, clients and caregivers are able to utilize this product in the comfort of their own environment and at a time that is convenient for them. It has been theorized that when learning situations are physically and psychologically relaxed, adults are more engaged and receptive to the process of learning (Caffarella, 2002). This product also addresses various roles and environments, which allows individuals to apply the information to personal goals and objectives. The learning style of adults is pragmatic, and they desire to apply what they are learning to their current situation (Caffarella, 2002). They prefer to not be passive in gaining knowledge, but rather they desire to be an active participant in the learning process.

Occupational therapists or other healthcare professionals can distribute this guide at any point within the rehabilitation process, and utilize the manual in a group setting or on an individual basis. Opportunities for self-reflection are available throughout the guide to enhance or maintain awareness of symptoms, and to potentially stimulate discussion with healthcare professionals, or other members of a group if used in a group setting, to assist in recognition and management of post-stroke fatigue.

CHAPTER IV

PRODUCTS/RESULTS

Research has determined that fatigue is a common symptom that occurs following a stroke and interferes with an individual's engagement in activities of daily living. Fatigue can be misinterpreted as depression, and therefore may be treated inappropriately or remain untreated. Fatigue is not often addressed by healthcare professionals; as a result, clients and their families are not receiving the proper education and resources to manage fatigue problems (Glader, Stagmayr, & Aspulund, 2002; Schepers, Visser-Meily, Ketelaar, & Lindeman, 2006).

The guide for daily living is intended to assist in the management of post-stroke fatigue symptoms to facilitate quality of life and well being. The content includes educational information for clients and caregivers in order to define and identify post-stroke fatigue, its possible causes and risk factors, and the potential impact on daily living. In addition, the guide offers a variety of post-stroke management strategies, which include instructions for recognizing fatigue symptoms, using energy conservation techniques, tips for staying active, and addressing the psychosocial aspects of living with fatigue. It is the hope that this guide will stimulate self-reflection and discussion with their occupational therapist and/or other healthcare providers in order to recognize and manage post-stroke fatigue.

Adult Learning Theory was selected for the development of the product due to "the fact that adults engage in an educational activity because of some innate desire for

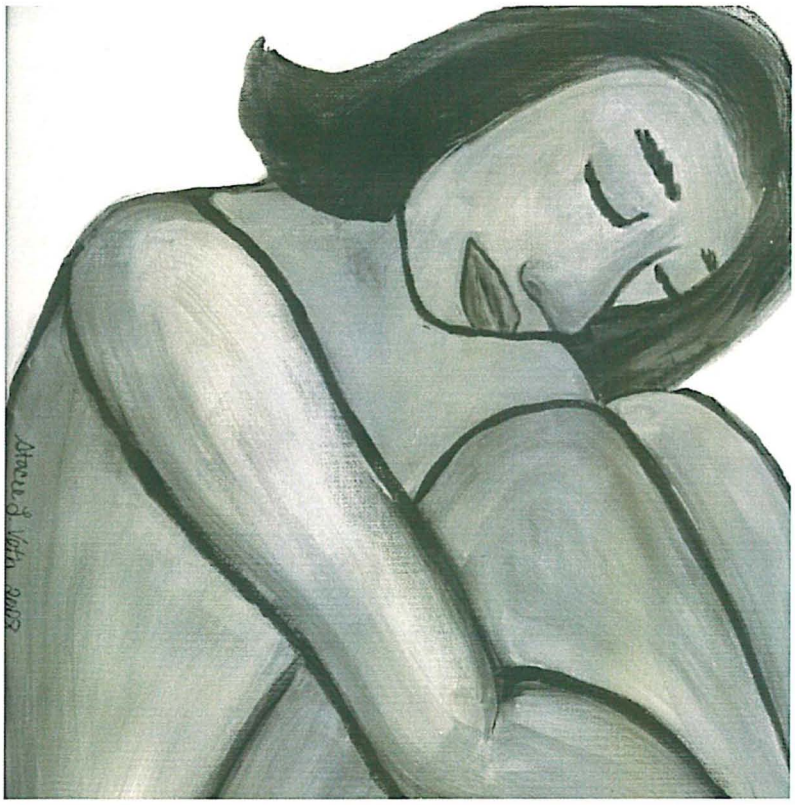
the developing of new skills, acquiring new knowledge, improving already assimilated competencies, or sharpening powers of self-insight…" (Brookfield, 2002, p.11). Adults have preferred and varying ways in which they process information, and adults are more willing to engage in learning if the learning is meaningful to them (Caffarella, 2002). Furthermore, adults learn best when they are presented with something they can apply in real-life situations (Knowles, Holton, & Swanson, 2005).

Adult Learning Theory provides the learner with the responsibility to make his or her own decisions. By increasing awareness of what the learner needs to know, individuals are able to make personal modifications and to effectively cope with real-life situations (Knowles et al., 2005); they prefer to not be passive in gaining knowledge, but rather they desire to be an active participant in the learning process (Caffarella, 2002).

In the following pages, the guide for daily living will be presented as a manual that can be distributed to clients and caregivers at any point within the rehabilitation process by occupational therapists or other healthcare professionals. The manual can also be utilized in a group setting or on an individual basis, with opportunities provided throughout for self-reflection to maintain or enhance self-awareness of symptoms.

Managing Post-Stroke Fatigue

A Guide for Daily Living for Clients and Caregivers



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May 2008

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Understanding Stroke

- Otherwise known as a Cerebrovascular Accident (CVA).
- A stroke occurs when there is a leakage or blood clot in the blood vessels that carry oxygenated blood and nutrients to the brain.
- Every year, approximately 700,000 Americans are diagnosed with a new or recurrent stroke.
- In 2007, medical costs and disability related to stroke cost Americans about $62.7 billion.

American Stroke Association, 2008

Types of Strokes

- Ischemic strokes, caused by a blood clot, account for 83% of all cases of stroke.
- Hemorrhagic strokes, caused by leakages in a blood vessel, account for 17% of all cases of stroke.
- Transient ischemic attacks, or TIAs, are similar to ischemic strokes but the symptoms last for a short period of time. TIAs are a warning sign of a possible major stroke and preventive steps should be taken. Talk to your physician.

American Stroke Association, 2008

Prevalence of Post-Stroke Fatigue

- In 2005, 30%-68% of stroke survivors experienced fatigue as a result of the stroke (Choi-Kwon, Han, Kwon, & Kim, 2005; Glader et al., 2002; Ingles et al., 1999; van der Werf, 2001).
- Fatigue has the most effect on physical versus psychosocial or cognitive activities (Choi-Kwon et al., 2005; Ingles et al., 1999).
- Fatigue is often one of the largest barriers to recovery.
- Many individuals report fatigue as their worst or one of their worst symptoms.
- Fatigue is a primary factor in the decrease in quality of life after stroke.

- Fatigue may occur soon or late after stroke, and it can persist for long periods of time after the stroke has occurred.
- 77% of individuals experience fatigue within the first week after onset of stroke (Choi-Kwon et al., 2005).
- 44% of individuals reported that fatigue was present more than 20 days per month (Choi-Kwon et al., 2005).

What is Post-Stroke Fatigue?

- Post-stroke fatigue does not have one definition and it can mean different things to different people.
- Although most people know what it feels like to be tired, post-stroke fatigue is more than feeling tired at the end of the day. Fatigue is when you get tired very quickly just from doing normal things or even when you are not doing anything.
- For some people, fatigue means decreased physical or mental energy, while others experience tiredness or have difficulty starting or finishing activities.
- Fatigue can occur in response to tiring activities or some people may experience continual exhaustion no matter what activity they perform.
- Fatigue associated with post-stroke fatigue typically does not go away completely. It is always present.
- Fatigue might be the result of a stroke or it might be the result of a disease that is separate from stroke.
- Fatigue may be characterized as muscle weakness or it may be characterized by people's perception of fatigue.

How often do you experience fatigue?

Has fatigue prevented you from doing something you wanted to do?

_____
_____
_____
_____

Do you experience mental or physical fatigue (or both)?

_____
_____
_____
_____

When do you experience fatigue? (For example, during a certain time of day or after a specific activity)

_____
_____
_____
_____

How Does Post-Stroke Fatigue Differ From Depression?

- Symptoms of fatigue and depression are often similar and it can be difficult to tell them apart.
- Individuals can experience post-stroke fatigue without feelings of depression, or both symptoms might occur at the same time.
- Fatigue can sometimes lead to feelings of depression and depression may worsen feelings of fatigue.
- Knowing whether you have depression, in addition to feelings of fatigue, will help manage symptoms and increase ability to cope.
- Depression is a matter to be discussed with your healthcare professional.

How Does Post-Stroke Fatigue Make You Feel?

- Fatigue symptoms differ amongst individuals.
- The level of fatigue can vary from a mild lack of energy to complete exhaustion.

Check all that apply:

☐ I do not have the energy to participate in activities that I used to be able to do before I had my stroke.

☐ My fatigue does not go away with rest.

- ☐ My fatigue occurs continuously no matter what activities I do.
- ☐ I feel anxious because I am having difficulty starting or finishing a task or activity.
- ☐ I have experienced a decrease in sexual activity.
- ☐ I have experienced a change in my eating habits.
- ☐ I have experienced a change in sleep patterns.
- ☐ I am experiencing more stress than usual because I have a lot to do and I do not have the energy to do it.
- ☐ I am not able to concentrate for extended periods of time.
- ☐ My fatigue has affected my relationships with family and friends.
- ☐ Fatigue has affected my driving performance.

It is important to discuss this checklist with your occupational therapist or physician. Use the space below for any questions or concerns .

_____
_____
_____
_____

Fatigue's Potential Impact on Daily Living

- Dependence with daily activities and self-cares
- Change in roles inside and outside of the home
- Decreased quality of relationships with others
- Transition to an assisted living facility or nursing home
- Poor general health, anxiety, pain, and depression
- Speech impairment
- Mobility deficits (decrease in strength, reduction in activity, decline in balance and gait)
- Decline in mental functioning
- Decreased cardiovascular system
- Predictor for mortality

Potential Causes of Post-Stroke Fatigue

- There are several possible causes of fatigue post-stroke:
    - Defects with hormone and stress levels
    - Decreased immune system responses
    - Altered brain pathways following a stroke
    - Deficits in nutritional and metabolic status

What questions would you like to ask your healthcare provider?

_____
_____
_____
_____
_____
_____

The Role of Caregivers in Managing Post-Stroke Fatigue

- Family members are typically involved with the family member for needs at home following hospital discharge.
- Family members as caregivers are team members with the stroke survivors.
- Caregivers are able to communicate the needs and concerns of the family member to their healthcare provider as an advocate.
- Research equipment and supplies that may be needed for home care and ask questions about availability and cost.
- Assist, as necessary, for finances and transportation.
- Seek out respite care to provide temporary relief of caregiving duties.
- Participate in educational classes with family members to increase awareness and understanding of symptoms and treatment.
- Ask questions to clarify information received in order to provide the best care for the family member.

- Encourage family member to practice skills learned in order to assist with recovery.
- Consult with an occupational therapist or other healthcare provider to find out what types of supports are available and how those supports can be accessed.
- Consult with occupational therapist or other healthcare provider to assist with all tasks, including health-related and day-to-day tasks.

What questions do you have for your occupational therapist or healthcare provider to assist with the transition from hospital to home?

_____

_____

_____

_____

_____

Sit et al., 2004

Role of an Occupational Therapist

- Provides comprehensive therapy that includes multiple intervention strategies such as training of sensory and muscle functions, training of cognitive functions, training of daily living skills, and education in coping and adapting.
- Enables individuals to gain skills to participate in self-care, work, and leisure activities that they desire or need to perform.
- "Efficiency Experts" who are uniquely qualified to provide education in energy conservation strategies, time management, proper body usage, and task performance (Mathiowetz et al., 2001).
- Designs and provides education on fatigue management strategies to promote successful, functional recovery.
- Makes recommendations for equipment that will assist in self care and home tasks.
- Provides customized splint increase function of the hand.
- Performs home evaluations to identify and remove barriers and potential hazards.

- Increases strength and endurance through treatment and home programming.
- Builds self-confidence and self-esteem through participation in meaningful activities.

American Occupational Therapy Association, 2002

Post-Stroke Fatigue Management Strategies

- Consult with your physician to rule out depression or other treatable diseases.
- Consult your physician regarding medications to help reduce the effects that fatigue has on pain, muscle tightness, and sleep disturbances.
- Keep a journal to help you determine which activities and medications are causing fatigue.
- Contact your physician with any concerns regarding changes in your activity or mood level.
- Take medications as prescribed by your physician.
- Contact your physician if medications seem to be increasing your level of fatigue.
- Participate in a regular exercise routine for physical and psychological benefits.
- Modify aerobic activities and use adaptive equipment as needed.
- Structure daily activities with required rest breaks.
- It is important to exercise even on days that you feel good in order to prevent an increase in symptoms.

What exercise or physical activities do you enjoy?

_____
_____
_____
_____
_____
_____

Of these activities, which will you discuss with your occupational therapist to learn modification techniques?

_____
_____
_____
_____
_____

- Use relaxation techniques
- Use meditation to keep stress levels low.
- Participate in activities that restore energy.
    - Read a book
    - Write in a diary
    - Watch a movie or TV
    - Talk with family or friends on the phone
    - Go for a leisurely walk
    - Volunteer
    - Start a new hobby
- Identify and modify the activities that create fatigue.
- Make adaptations to the environment to conserve energy.
    - Group items together that are needed to complete a task.
    - Keep items used most frequently at a close distance and on the main level of your home.
    - Position items that are placed too high or too low at counter height.
    - Place a stool or chair in areas where you typically stand to complete activities (for example, in the kitchen or laundry room).
    - Install grab bars and/or shower chair in the bathtub.
- Join a community support group.
    - To discuss post-stroke management strategies.
    - Receive feedback on successes and failures of strategies used.
    - To gain social participation and support.
- Prioritize and/or delegate daily activities in order to have the energy needed to complete a task.
- Simplification of work activities by decreasing the amount, pre-plan, utilize appropriate body mechanics,

and utilize efficient methods and proper equipment.

- Continue to talk with your family, friends, and co-workers about your fatigue and how they can help you.
- Be honest with yourself about your limitations.
- Participate in meaningful activities to promote health and well-being.
- Seek out help from an occupational therapist or another healthcare professional for problems that you are not able to solve on your own.

Resources

- American Stroke Association www.strokeassociation.org
- National Stroke Association www.stroke.org
- American Occupational Therapy Assocation www.aota.org

Use the space below to list resources available in your community to assist in management of post-stroke fatigue.

_____

_____

_____

_____

_____

References

Aaronson, L. S., Teel, C. S., Cassmeyer, V., Neuberger, G. B., Pallikkathayil, L., Pierce, J., Press, A. N., Williams, P. D., & Wingate, A. (1999). Defining and measuring fatigue. *Image: Journal of Nursing Scholarship, 31,* 45-50.

Chaudhuri, A. & O Behan, P. (2004). Fatigue in neurological disorders. *The Lancet, 363,* 978-988.

Choi-Kwon, S., Han, S. W., Kwon, S. U., & Kim, J. S. (2005). Poststroke fatigue: Characteristics and related factors. *Cerebrovascular Diseases, 19,* 84-90.

de Groot, M. H., Phillips, S. J., & Eskes, G. A. (2003). Fatigue associated with stroke and other neurologic conditions: Implications for stroke rehabilitation. *Archives of Physical Medicine and Rehabilitation, 84,* 1714-1720.

Fisk, J. D., Ritvo, P. G., Ross, L., Hasse, D. A., Marrie, T. J., & Schlech, W. F. (1994).Measuring the functional impact of fatigue: Initial validation of the fatigue impact scale. *Clinical Infectious Diseases, 18,* S79-83.

Glader, E., Stegmayr, B., & Asplund, K. (2002). Poststroke fatigue: A 2-year follow-up study of stroke patients in Sweden. *Stroke, 33*, 1327-1333.

Holberg, C., & Finlayson, M. (2007). Factors influencing the use of energy conservation strategies by persons with multiple sclerosis. *American Journal of Occupational Therapy 61*(1), 96-107.

Ingles, J. L., Eskes, G. A., & Phillips, S. J. (1999). Fatigue after stroke. *Archives of Physical Medicine and Rehabilitation, 80*, 173-178.

Jaracz, K., Mielcarek, L., & Kozubski, W. (2007). Clinical and psychological correlates of poststroke fatigue: Preliminary results. *Neurologia I Neurochirurgia Polska, 41,* 36-43.

Mathiowetz, V., Matuska, K. M., & Murphy, M. E. (2001). Efficacy of an energy conservation course for persons with multiple sclerosis. *Archives of Physical Medicine and Rehabilitation, 82,* 449-456.

Matuska, K., Mathiowetz, V., & Finlayson, M. (2007). Use and perceived effectiveness of energy conservation strategies for managing multiple sclerosis fatigue. *American Journal of Occupational Therapy, 61,* 62-69.

Mead, G., Lynch, J., Greig, C., Young, A., Lewis, S., & Sharpe, M. (2007). Evaluation of fatigue scales in stroke patients. *Stroke, 38*, 2090-2095.

Michael, K. (2002). Fatigue and stroke. *Rehabilitation Nursing, 27,* 89-94,103.

Michael, K. M., Allen, J. K., & Macko, R. F. (2006). Fatigue after stroke: Relationship to mobility, fitness, ambulatory activity, social support, and falls efficacy. *Rehabilitation Nursing, 31,* 210-217.

Schepers, V. P., Visser-Meily, A. M., Ketelaar, M., & Lindeman, E. (2006). Poststroke fatigue: Course and its relation to personal and stroke-related factors. *Archives of Physical Medicine and Rehabilitation, 87,* 184-188.

Sit, J. W. H., Wong, T. K. S., Clinton, M., Li, L. S. W., & Fong, Y. (2004). Stroke care in the home: The impact of social support on the general health of family caregivers. *Journal of Clinical Nursing, 13,* 816-824.

Staub, F. & Bogousslavsky, J. (2001). Fatigue after stroke: A major but neglected issue. *Cerebrovascular Diseases, 12,* 75-81.

Staub, F., & Bogousslavsky, J. (2001). Post stroke depression or fatigue? *European Neurology, 45*, 3-5.

Steultjens, E. M. J., Dekker, J., Bouter, L. M., van de Nes, J. C. M., Cup, E. H. C., van den Ende, C. H. M., Landi, F., & Bernabei, R. (2003). Occupational therapy for stroke patients: A systematic review. *Stroke, 34,* 676-687.

Swain, M. G. (2000). Fatigue in chronic disease. *Clinical Science, 99,* 1-8.

Tyrrell, P. J., & Smithard, D. G. (2006). Fatigue after stroke. *Therapy, 2*(6), *865-869.*

van de Port, I. G. L., Kwakkel, G., Schepers, V. P. M., Heinemans, C. T. I., & Lindeman, E. (2007). Is fatigue an independent factor associated with activities of daily living, instrumental activities of daily living and health-related quality of life in chronic stroke? *Cerebrovascular Disease, 23,* 40-45.

van der Werf, S. P., van den Broek, H. L. P., & Anten Gijs Bleijenberg, H. W. M. (2001). Experience of severe fatigue long after stroke and its relation to depressive symptoms and disease characteristics. *European Neurology, 45,* 28-33.

Welham, L. (1995). Occupational therapy for fatigue in patients with multiple sclerosis. *British Journal of Occupational Therapy, 58*(12), 507-509.

CHAPTER V

SUMMARY

Research has determined that fatigue is a frequent symptom following a stroke and is recognizied to have significant functional consequences. Few studies have determined that post-stroke fatigue can occur independent of additional consequences following a stroke. In particular, fatigue may be misinterpreted as depression and therefore fatigue may be treated inappropriately or remain untreated by health care professionals. As a result, clients and their families are not receiving the proper education and resources to manage fatigue (Glader, Stegmayr, & Aspuland, 2002; Schepers, Visser-Meily, Ketelaar, & Lindeman, 2006). The purpose of this project was to develop a guide for daily living for clients and caregivers to assist in the management of post-stroke fatigue.

A review of literature was conducted to determine what has been done in the healthcare professions and the field of occupational therapy regarding management of post-stroke fatigue. A guide for daily living to manage post-stroke fatigue was developed for clients and caregivers incorporating adult learning principles. The contents address the most prevalent needs, as identified in the literature review, of individuals that are suffering from post-stroke fatigue. The role of occupational therapy is incorporated throughout this project as occupational therapists are uniquely qualified to educate individuals in energy conservation strategies, management of time, proper body mechanics, and performance of a task. Furthermore, the purpose of the occupational

therapy profession "is to enable individuals to participate in self-care, work, and leisure activities that they want or need to perform" (Mathiowetz et al., 2001).

There are limitations to researching post-stroke fatigue. First, fatigue lacks a universal definition in which to categorize and measure in order to develop appropriate interventions for treatment. Without a concrete definition, this symptom remains undiagnosed and untreated by health professionals. Second, lack of an objective method of measuring post-stroke fatigue makes comparison between studies difficult (Ingles et al., 1999). Lastly, further identification of post-stroke management strategies and their effectiveness, including occupational therapy interventions, is critical to optimize rehabilitation and recovery.

This guide for daily living provides educational information for clients and caregivers in order to define and identify post-stroke fatigue, its possible causes and risk factors, and its potential impact on daily living. In addition, it offers a variety of post-stroke management strategies which include instructions for recognizing fatigue symptoms, using energy conservation techniques, tips for staying active, and addressing the psychosocial aspects of living with fatigue. This educational guide can be distributed by occupational therapists or other healthcare professionals in all stages of the recovery process to facilitate quality of life and well-being. It can also be utilized in a group setting or on an individual basis, with opportunities provided throughout for self-reflection to maintain or enhance self-awareness of symptoms.

Although several factors have been identified in relation to post-stroke fatigue, further research is needed to better understand the etiology and symptoms associated with post-stroke fatigue. The recognition of the need for assessment and treatment of post-

stroke fatigue by occupational therapists and other healthcare professionals is another initial step toward development of appropriate intervention. Further research is also needed to support specific interventions for patients following stroke and to facilitate evidence-based OT. Client, caregiver, and occupational therapy focus groups are recommended to determine if the created product is effective and meets the needs in regards to management of post-stroke fatigue. In addition, distribution of the product to clinicians in rehabilitation facilities is recommended to obtain feedback on ways to enhance or modify the guide. Results of the suggested recommendations will be valuable to improve the product as necessary.

Research on project efficacy could begin with development of a feedback survey and/or focus group questions. This would be followed by the University of North Dakota IRB approval of the study of client and occupational therapy feedback. After gathering and analyzing product outcome feedback, publication of this guide for daily living with post-stroke fatigue will be pursued.

APPENDIX

SCHOOL OF MEDICINE & HEALTH SCIENCES
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I hereby give my permission to the University of North Dakota, its agents, successors, assigns, clients and purchasers of its services and/or products, to use my original artwork/picture and my name.

Date: April 13, 2008

Signed: Stacie Lee Voth

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REFERENCES

Aaronson, L. S., Teel, C. S., Cassmeyer, V., Neuberger, G. B., Pallikkathayil, L., Pierce, J., Press, A. N., Williams, P. D., & Wingate, A. (1999). Defining and measuring fatigue. *Image: Journal of Nursing Scholarship, 31,* 45-50.

Brookfield, Stephen D. (1986). Adult learners: Motives for learning and implications for practice. In S. D. Brookfield (Ed.), *Understanding and facilitating adult learning: A comprehensive analysis of principles and effective practices* (pp. 1-24). San Francisco, CA: Jossey-Bass.

Caffarella, Rosemary S. (2002).The interactive model of program planning. In R. S. Caffarella (Ed.), *Planning programs for adult learners: A practical guide for educators, trainers, and staff developers* (pp. 20-36). San Francisco, CA: Jossey-Bass.

Chaudhuri, A. & O Behan, P. (2004). Fatigue in neurological disorders. *The Lancet, 363,* 978-988.

Choi-Kwon, S., Han, S. W., Kwon, S. U., & Kim, J. S. (2005). Poststroke fatigue: Characteristics and related factors. *Cerebrovascular Diseases, 19*, 84-90.

de Groot, M. H., Phillips, S. J., & Eskes, G. A. (2003). Fatigue associated with stroke and other neurologic conditions: Implications for stroke rehabilitation. *Archives of Physical Medicine and Rehabilitation, 84,* 1714-1720.

Fisk, J. D., Ritvo, P. G., Ross, L., Hasse, D. A., Marrie, T. J., & Schlech, W. F. (1994).

Measuring the functional impact of fatigue: Initial validation of the fatigue impact scale. *Clinical Infectious Diseases, 18,* S79-83.

Glader, E., Stegmayr, B., & Asplund, K. (2002). Poststroke fatigue: A 2-year follow-up study of stroke patients in Sweden. *Stroke, 33*, 1327-1333.

Holberg, C., & Finlayson, M. (2007). Factors influencing the use of energy conservation strategies by persons with multiple sclerosis. *American Journal of Occupational Therapy 61*(1), 96-107.

Ingles, J. L., Eskes, G. A., & Phillips, S. J. (1999). Fatigue after stroke. *Archives of Physical Medicine and Rehabilitation, 80*, 173-178.

Jaracz, K., Mielcarek, L., & Kozubski, W. (2007). Clinical and psychological correlates of poststroke fatigue: Preliminary results. *Neurologia I Neurochirurgia Polska, 41,* 36-43.

Knowles, M. S., Holton III, E. F., & Swanson, R. A. (2005). A theory of adult learning: Andragogy. In M. S. Knowles, E. F. Holton III, & R. A. Swanson (Eds.), *The adult learner* (pp. 35-72). Burlington, MA: Elsevier Inc.

Mathiowetz, V., Matuska, K. M., & Murphy, M. E. (2001). Efficacy of an energy conservation course for persons with multiple sclerosis. *Archives of Physical Medicine and Rehabilitation, 82,* 449-456.

Matuska, K., Mathiowetz, V., & Finlayson, M. (2007). Use and perceived effectiveness of energy conservation strategies for managing multiple sclerosis fatigue. *American Journal of Occupational Therapy, 61,* 62-69.

Mead, G., Lynch, J., Greig, C., Young, A., Lewis, S., & Sharpe, M. (2007). Evaluation of fatigue scales in stroke patients. *Stroke, 38*, 2090-2095.

Michael, K. (2002). Fatigue and stroke. *Rehabilitation Nursing, 27,* 89-94,103.

Michael, K. M., Allen, J. K., & Macko, R. F. (2006). Fatigue after stroke: Relationship to mobility, fitness, ambulatory activity, social support, and falls efficacy. *Rehabilitation Nursing, 31,* 210-217.

Schepers, V. P., Visser-Meily, A. M., Ketelaar, M., & Lindeman, E. (2006). Poststroke fatigue: Course and its relation to personal and stroke-related factors. *Archives of Physical Medicine and Rehabilitation, 87,* 184-188.

Sit, J. W. H., Wong, T. K. S., Clinton, M., Li, L. S. W., & Fong, Y. (2004). Stroke care in the home: The impact of social support on the general health of family caregivers. *Journal of Clinical Nursing, 13,* 816-824.

Staub, F. & Bogousslavsky, J. (2001). Fatigue after stroke: A major but neglected issue. *Cerebrovascular Diseases, 12,* 75-81.

Staub, F., & Bogousslavsky, J. (2001). Post-stroke depression or fatigue? *European Neurology, 45*, 3-5.

Steultjens, E. M. J., Dekker, J., Bouter, L. M., van de Nes, J. C. M., Cup, E. H. C., van den Ende, C. H. M., Landi, F., & Bernabei, R. (2003). Occupational therapy for stroke patients: A systematic review. *Stroke, 34,* 676-687.

Swain, M. G. (2000). Fatigue in chronic disease. *Clinical Science, 99,* 1-8.

Tyrrell, P. J., & Smithard, D. G. (2006). Fatigue after stroke. *Therapy, 2*(6), *865-869.*

van de Port, I. G. L., Kwakkel, G., Schepers, V. P. M., Heinemans, C. T. I., & Lindeman, E. (2007). Is fatigue an independent factor associated with activities of daily living, instrumental activities of daily living and health-related quality of life in chronic stroke? *Cerebrovascular Disease, 23,* 40-45.

van de Port, I. G. L., Kwakkel, G., van Wijk, I., & Lindeman, E. (2006). Susceptibility to deterioration of mobility long-term after stroke: A prospective cohort study. *Stroke, 37,* 167-171.

van der Werf, S. P., van den Broek, H. L. P., & Anten Gijs Bleijenberg, H. W. M. (2001). Experience of severe fatigue long after stroke and its relation to depressive symptoms and disease characteristics. *European Neurology, 45,* 28-33.

Welham, L. (1995). Occupational therapy for fatigue in patients with multiple sclerosis. *British Journal of Occupational Therapy 58*(12), 507-509.